Standardised Multilingual Reporting: Health Technology Assessment

Presented by Dr Jack Nunn

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Aims of presentation

- To explore the current challenges for HTA, including the current limitations and inconsistencies in sharing data about HTA processes globally
- To describe how Standardised Data on Initiatives (STARDIT) can be used to address some of these limitations by providing a way to report data more consistently
- Invite feedback and discussion on the next version of STARDIT – Version One

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An expert is in the eye of the beholder

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An expert is in the eye of the beholder

I speak from personal and professional experience

Today I am not speaking on behalf of any organisations and represent myself

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About the speaker – Dr Jack Nunn

- **Founder and Director of the charity 'Science for All'** (voluntary/paid)
- **Medical Services Advisory Committee Evaluation Sub-committee** and others (paid)
- **Public Involvement Strategic Lead at La Trobe University** (employed)
- **Australian Genomics** working group 'Involve Australia' (paid)

Volunteer

- **Cochrane Council** (voluntary)
- **Co-Chair - UNESCO Citizen Science & Open Science Community of Practice** (voluntary)
- **Strategy Liaison - WikiJournals** (voluntary)

Relevant experience

- **Completed a PhD in 2022 exploring genomic research and how people can be involved** in shaping the future of research, and reporting involvement in standardised ways
- **Nearly 15 years of experience involving people** (including patients and the public) in health and social care research, and in environmental research and citizen science

Disclosures

- Travel and accommodation funded Australian Federal Department of Health

- Time at the conference is given pro bono by Science for All

- I have **never** been employed by a for-profit company,
- Science for All has never been funded or received payment or in-kind support from any for-profit company (including pharmaceutical companies)

Authorship, acknowledgements and involvement

- This presentation was written by **Jack Nunn**, and co-authored by **Gillian Mason**

- Input was invited from people with experience of working in HTA around the world, in particular, as public and patient representatives

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What are the main challenges for HTA?*

- Limited funding
- Lack of technical capacity
- Stakeholder engagement and involvement
- Time constraints
- Political interference
- Data quality
- Heterogeneity of evidence
- Uncertainty
- Value judgments

*According to ‘Google Bard’ 21st May 2023

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What are the main challenges for HTA? How could STARDIT help?

- Limited funding
- Lack of technical capacity
- Stakeholder engagement and involvement
- Time constraints
- ~~Political interference~~ Opaque influences and interests
- Data quality
- Heterogeneity of evidence
- Uncertainty
- Value judgments

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We need evidence informed methods of assessing health technology, including involving different stakeholders

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We need evidence informed methods of assessing health technology, including involving different stakeholders

Public? People? Payers?

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We need evidence informed methods of assessing health technology, including involving different stakeholders

We need improved transparency

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STARDIT

Standardised Data on Initiatives

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Learn more at:
ScienceForAll.World/STARDIT

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STARDIT

An open access data-sharing system to standardize how information about initiatives is reported.

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Learn more at:
ScienceForAll.World/STARDIT

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About STARDIT

2019 → 2020 → 2021 → 2022

Stage 1: **Alpha version development**			Stage 2: **Public Consultation**		Stage 3: **Beta version development**	
July	August	September	September	Oct-Dec	2020	2021
STARDIT co-designed with a small team of experts	**Draft version shared for comment**	**Alpha version shared as pre-print in public**	**Combined face to face and video discussions hosted in London**	**Global feedback on Alpha version invited, analysed and shared in public report**	**Beta version developed and content shared as in public domain**	**Feedback collated and incorporated – STARDIT Beta submitted for peer review**
Co-design led by Science for All with global stakeholders involved in the following tasks at each stage:						
					STARDIT Beta	
Co-designing STARDIT	**Sharing views and ideas**	**Feedback on co-design process**	**Detailed feedback on feasibility and implementation**	**Feedback on every aspect of Alpha version**	**Feedback on every aspect of Beta version, including technical implementation**	

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Learn more at:
ScienceForAll.World/STARDIT

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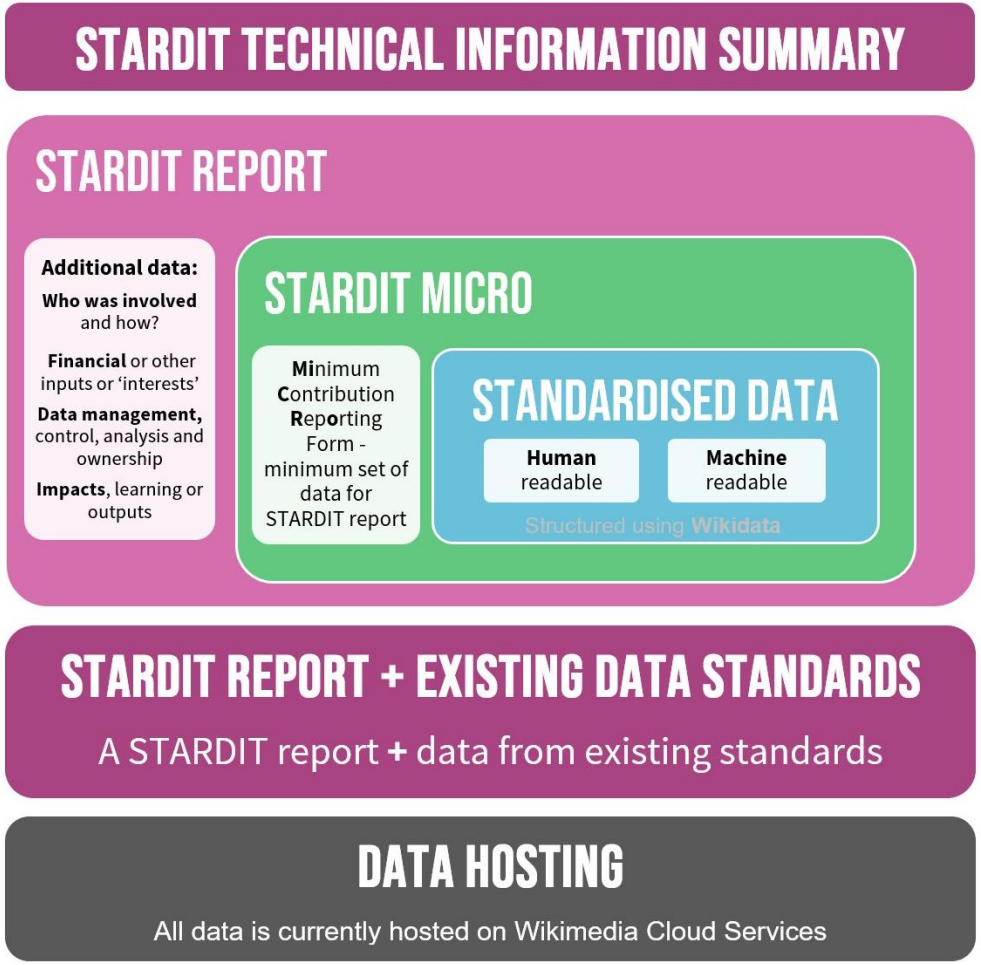
About STARDIT


STARDIT TECHNICAL INFORMATION SUMMARY
STARDIT REPORT
Additional data:
Who was involved and how?
Financial or other inputs or 'interests'
Data management, control, analysis and ownership
Impacts, learning or outputs
STARDIT MICRO
Minimum Contribution Reporting Form - minimum set of data for STARDIT report
STANDARDISED DATA
Human readable
Machine readable
Structured using Wikidata
STARDIT REPORT + EXISTING DATA STANDARDS
A STARDIT report + data from existing standards
DATA HOSTING
All data is currently hosted on Wikimedia Cloud Services

Governance:

- STARDIT Steering Committee hosted by Science for All
- STARDIT Moderation Committee oversees content, API access
- Wiki Journal Editorial Boards give transparent advice

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Organisations and STARDIT reports*

- Australian Genomics
- La Trobe University
- University of Queensland
- Monash University
- University of Liverpool
- Olga Tennison Autism Research Centre (OTARC)
- Science for All
- Health Research Authority (UK)
- MANT Centre for Public Health Research (India)
- Cochrane (International)
- Intergovernmental Platform on Biodiversity and Ecosystem Services (IPBES)
- Wiki Journals (International)

*completed by people working for or with those organisations

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Example STARDIT reports

People affected by a **rare disease**, working with charity ausEE

How people with rare diseases were involved in research

'Involving people affected by a rare condition in shaping future genomic research' doi.org/10.1186/s40900-021-00256-3

Half-siblings who share the same donor father, from an **international group** of 20+

How people with 'shared ancestry' were involved in research

'Co-designing genomics research with a large group of donor-conceived siblings' doi.org/10.1186/s40900-021-00325-7

Australia's largest trial

ASPREE

Planning multi-generational study

How elderly research participants were involved in the co-design of a study

'Involving elderly research participants in the co-design of a future multi-generational cohort study' doi.org/10.1186/s40900-021-00271-4

Aboriginal personalised medicine project

POCHE INDIGENOUS HEALTH NETWORK

The co-design process for a precision medicine research protocol, working with Aboriginal Australians

A Pathway to Precision Medicine for Aboriginal Australians: A Study Protocol doi.org/10.3390/mps4020042

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Applications of STARDIT in HTA

From 'Standardised data on initiatives—STARDIT: Beta version':
Nunn, J.S., Shafee, T., Chang, S. et al. (2022). https://doi.org/10.1186/s40900-022-00363-9

Reporting: "**Assessment process for pharmaceuticals, devices, procedures and organisational systems used in health care**"

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Reporting: "**Assessment process for pharmaceuticals, devices, procedures and organisational systems used in health care**"

- **Process for deciding health technology assessment** (oversight and scrutiny)
- **Sources of data and evidence**
- **Process for deciding and measuring outcomes**
- **Experts involved, people affected involved**
- **Conflicting or competing interests** (kind of interest – financial, personal etc)
- **Outcomes from assessment decisions** (including outcomes measured by those affected by assessment decisions)
- **Collation of adverse event reports** from Governments and reputable sources
- **Assessment evaluation** (did it achieve what was intended?)
- **Results of economic evaluations**

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HTA Challenges: STARDIT Use Cases

Challenge	STARDIT could be used to improve data sharing about:
Limited funding	
Lack of technical capacity	
Time constraints	
Stakeholder engagement and involvement	
Opaque influences and interests	
Data quality	
Heterogeneity of evidence	
Value judgments	

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Limited funding	Multiple international HTA processes; effectiveness and efficiency of different HTA processes themselves (and how that was determined); availability of data from HTA processes that can be reused (FAIR data), 'costs' and 'prices' in different countries* **Note on equity**: such data could **facilitate decision making in LMIC countries**
Lack of technical capacity	
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Stakeholder engagement and involvement	Which 'stakeholders' were involved (or excluded), preferences of stakeholder, methods of involvement (in/formal, un/paid), tasks they did, communication modes, how involvement affected HTA process, impacts & outcomes of involvement
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Value judgments	Who's values we integrated (and who's were not), and 'how' (methodology)

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*Question: Can we improve publicly available data about ‘costs’ and ‘prices’ of HTA items?

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- STARDIT can improve accessibility to this data, and thus accountability

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Summary

- **STARDIT can help create high-quality standardized information about HTA processes** that can be accessed and edited by anyone.
- **STARDIT enables data reporting at all stages of the HTA process** and **works in multiple languages**. This allows stakeholders involved in or affected by HTA processes (including patients, the public, Indigenous peoples, and people from industry) to appraise and edit information and to self-identify the labels and terminology used to describe them.
- STARDIT offers those conducting HTA access to **standardized information that enables well-founded comparisons of the effectiveness of different HTA methods**, including the most effective methods of involving stakeholders.
- STARDIT allows anyone to access and contribute data about HTA processes, which can **support participatory ways of working and help improve the equity and quality of HTA processes worldwide**.

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Get involved

- **Anyone can complete a STARDIT report for free**, today (Beta version)
- Get involved with **co-authoring an article about using STARDIT**
- Ask for support in **creating reports or training machines to create them**
- **Join our international working group:**

ScienceForAll.World/STARDIT

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Questions and Discussion

- People can self-identify to terminology to describe themselves; **could STARDIT be used to describe stakeholder involvement more precisely**, including stakeholder grouping and mapping respective interests? (e.g. people affected, people living with, people paying for)
- **Could STARDIT provide more transparency** about how patients, people affected and other stakeholders have worked with pharmaceutical companies, **including any funding of activities,** helping critically appraise information?
- Would it be helpful for STARDIT to **report how people were involved who have a specific subjective lived-experience**, including specific DNA variations and phenotypes?
- Could STARDIT be used to **describe different people's values and priorities**, including integrating environmental outcomes and other 'outcomes of importance'?

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About this document

- This document was created by Jack Nunn for Science for All on 26th June 2023, to accompany a presentation given for the HTAi Conference.
- This document is a copy of the presentation slides given for the presentation ‘Standardised Multi-Lingual Reporting of Health Technology Assessment and Stakeholder Involvement’.
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- Contact Jack.Nunn@ScienceForAll.World and learn more at ScienceForAll.World.